

Aberystwyth University

Homecare and the informal information grapevine: implications for the electronic record in social care

Urquhart, Christine; Cooper, Janet

Published in:
Health Informatics Journal

Publication date:
2008

Citation for published version (APA):

Urquhart, C., & Cooper, J. (2008). Homecare and the informal information grapevine: implications for the electronic record in social care. *Health Informatics Journal*, 59-69. <http://hdl.handle.net/2160/510>

General rights

Copyright and moral rights for the publications made accessible in the Aberystwyth Research Portal (the Institutional Repository) are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Aberystwyth Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Aberystwyth Research Portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

tel: +44 1970 62 2400
email: is@aber.ac.uk

Homecare and the informal information grapevine – implications for the electronic record in social care

Janet Cooper¹, Christine Urquhart²

¹ Community Studies Department, Truro College, College Road, Truro, TR1 3XX, UK

² Department of Information Studies, University of Wales Aberystwyth, SY23 3AS, UK, cju@aber.ac.uk, tel. 01970-622162

Abstract

This article explores informal information exchange in social care, and discusses implications for formal monitoring with an electronic social care record (ESCR). Six homecare settings were studied over 14 months between 2001 and 2002. Participant observation methods were used with the recipients of homecare (n=7) and in-depth interviews plus participant observation with formal care workers (n=31). Allied healthcare professionals (n=9) and homecare managers (n=5) were interviewed, as were 2 family members. The findings show that assumptions about monitoring of care processes may be faulty, and that trust and negotiation are important aspects of the care delivery. Modelling of the business processes indicates that roles and responsibilities for managing a care plan may shift, with the consequence that information can be omitted from a formal record, if care workers selectively withhold information from care managers. The article concludes that any formal record needs to allow for the extensive negotiation involved in needs assessment, and monitoring of care plans.

Keywords: Home care services; Homemaker services; Medical records systems, computerized; Systems analysis

Introduction

Since the late 1990s health and social care services in the UK for the growing numbers of older people have shifted towards community, rather than institutional provision [1]. More care is provided by formal care workers who deliver social and personal care (homemaker services) in a client's home supplemented by visits from community health service staff for nursing care needs. There are targets for English local authorities to meet on provision of intensive home care for older people [2], and in 2002, nearly 3 million contact hours of home help and home care were provided to around 366,800 households in England, with the number of contact hours provided by the independent sector increasing at a steady rate.[3] . Home nursing and personal care services are organised and funded in different ways in other countries within the UK, but trends are similar. In Wales, the setting of the research, 12.6 million hours of home were provided in 2003, an increase of 1.4% on the previous year, and on average 60% provided from the independent sector.[4] Efficient management of homecare

requires efficient and timely recording and exchange of information between mobile homecare workers, agencies, local authorities and health services. This paper discusses information collection and information exchange in homecare in a setting in Wales, based around provision of homecare by an independent agency. The research examined formal and informal information flows, and the reasons for some of the observed problems, using business process modelling. The paper concludes by considering the implications for development of an electronic social care record (ESCR).

Background

Homecare settings are difficult areas to access for researchers, but several studies attest to poor communication between health and social care providers [5] [6] [7], and between homecare workers themselves[8]The English information strategy for social care [9] established principles for information management in social care, and the consultation document 10 *Defining the Electronic Social Care Record* examined how these principles would apply to electronic recording and document management in social care.

Implementation has consequences for the National Service Framework for Older People (NSF) proposals in the UK for a one-stop single assessment.[11] There are obvious issues of confidentiality for a combined and more widely accessible record in homecare.[12] Studies of nursing documentation and exchange of information between nursing staff often indicate that documentation may be incomplete, or at least that the formal documentation may be incomplete, with more emphasis placed by some nurses on their own personal records or 'scraps'.[13]There is some doubt whether nursing records (formal) affect nursing practice and patient care outcomes,[14] suggesting that documentation may merely fulfil narrow administrative needs. In interactions between informal carers and healthcare workers, information and access to information, govern the working relationships between informal carers and professional carers and the legitimization of competence, with both parties acting as gatekeepers to privileged information.[15] Important information for the care of the individual may be divulged gradually, and informally. The organisation of care for older people is often provided by teams, nominally, but studies have found that so-called teams often lack the necessary collaborative structures, with hierarchical structures evident instead, and management perceived as remote.[16] A randomized trial of two quality improvement strategies for public, community-based long-term care, in a US setting, suggested that improvements could be assessed although the effect sizes (for client satisfaction and perception of needs met) were small.[17]

Research methods

Overt participant observation and in-depth interviews were used to obtain as real a picture as possible of information flows and information management in homecare. The research was conducted as doctoral research, funded by the Arts and Humanities Research Board (now AHRC, Arts and Humanities Research Council). For ethical reasons, these vulnerable care recipients were not interviewed and field notes were recorded offsite. Care recipients were thus observed but not interviewed. The researcher [JC] performed dual roles as care worker for an independent care agency and fieldworker, ensuring access to the setting, building of trust and eventual acceptance by study participants. Triangulation was achieved through verification of findings from observations, casual conversations and interview responses. Overall, six settings involving seven clients were observed over an 18 month period, and 31 care workers, 2 family members, 5 care managers and 9 allied professionals were interviewed, including some care staff working directly for the local authority's social services. Sampling was largely purposive. The qualitative software package, NVivo was used to code and assist in data analysis.

Findings

Findings are presented according to some of the main processes that underpin the creation, and updating of a formal record of care (gathering information for a care package, monitoring of care) and some of the problems observed that might lead to monitoring information not being available, or withheld. Most quotations are derived from care staff working for the independent agency, but some (noted accordingly) originate from interviews with local authority staff.

Gathering information for a care package

Care managers must gather as much relevant client information as possible before establishing a new care package, or a major review of an existing one. This information is vital to decisions about the extent and intensity of care, the selection of the care team, and its composition.

An inappropriate package results from inappropriate information being collected or disseminated at any stage in the life of the care package. This can arise when clients do not reveal details about their situation to care managers, but only to care workers.

'Now what was a crisis on day one, when I go and visit on day two Mrs So-and-so is sitting there fully clothed - she hasn't been dressed for six months - fully clothed, make up on, "tea dear?" They try and present a different picture to us...' (Care Manager3)

In essence, the client was making an effort for the care manager and distorting the presentation of her care needs. A colleague reiterated the point that they often left a client's home with a distorted picture, which usually emerged over time,

'When you have been working with the client, or the care assistant has been going in, you get feedback... two or three weeks down the line you realise that the situation is not as you first thought' (Care Manager2)

Care managers acknowledged the difficulty of collecting information during the initial home visit:

'We are only given information that the client wants us to have, we are a stranger going into their home... and we are asking, probing for some quite personal information...' (Care Manager3)

Many local authority care packages created on the basis of an initial assessment may change within the first few weeks after implementation.

'Um, I think carers go out and are faced with circumstances that they are not prepared for, that case managers, uh social workers don't see..., I can't remember the exact figure, we did do an exercise... last year looking at care plans and something like 70% of care plans change within the first week or so, because when the carer goes out, in fact the care is not really what the person either wants, or needs' (Care Manager for the local authority)

Comments from the private sector indicate that care packages also change at an early stage:

'...because a lot of the information that the social worker has and the care-plan that's set up isn't really what's needed. Or, what they feel they need, they may feel that

person needs washing and dressing, whatever..., the client themselves, "no, I can wash and dress, but I need help in other areas." ' (Other agency Care Worker3)

Problems are intensified when ethnic minority members require homecare. Several care workers working in cross-cultural settings commented on the paucity of information given to them by care managers. The local authority's care workers reported similar issues. Care managers failed to collect appropriate information. Consequently care workers were ill informed, and hence were ill equipped to cope in particularly sensitive situations, a problem when high expectations of Asian-Indian for family support co-exist with high expectations for state support, and an awareness that family support may not be forthcoming.¹⁸.

Information exchange

The agency that was the setting for the research provided care to highly dependent older people who often required intensive care, provided over hours rather than in short visits to provide meals, or to assist the client in getting up or going to bed. Information was exchanged informally with other care workers at shift changeover, and formally in the logbooks. Often vital information might be put on post-it notes on the fridge, to ensure that the next care worker would not miss a warning or a request to check a possible concern.

‘Um, uh sometimes we just need to be aware of certain 'things.' Um that may not happen but we just make others aware of it, don't forget to check that, just in case.’
(Care Worker20)

Care workers took advantage of chance meetings outside work to pass on information.

‘I know we are not supposed to talk about our clients, but you have got to when you are working with one particular client, and somebody else is going in, say they are going in teatime. And you say, well this morning when I was in Mrs So-and-so, there were these problems, oh, she's very distressed about a situation. And you know you'd pass that information on, so we do need to communicate with one another, and it's not talking about them. It's talking...for them really’ (Care Worker30)

Constant flux

Client situations can change rapidly (as seen in Care Manager3's comment above) and any change needs to be immediately reflected in the client record. Last minute discharges from hospital, emergency admissions, changes to a client's health status, or a care worker's crisis must be relayed to care managers quickly for them to act upon the information. In practice, this did not always happen and care managers were not always updated. There were frequent problems between care managers and social workers with regard to a lack of communication and information exchange. Care managers complained that some social workers were difficult to contact:

'to get hold of a social worker is almost impossible'. (Care Manager3)

Family members reiterated this point, and some social workers also claimed that it was difficult to communicate with their colleagues.

Problems with information availability

Access to information was a problem for on-call managers who had restricted access to the agency's client database. Limited access to information impinged upon the delivery of homecare at particularly sensitive periods – out of office hours when fully-fledged managers were reluctant to provide support to the on-call manager, who had responsibility for helping the care worker:

'I didn't feel as if I was trusted with enough information to make me work independently as I would have liked to have done' (Care Worker23)

On-call managers relied on personal relationships with particular care workers to glean 'local' client information from them, which was often urgently required. The success of these relationships was based on mutual trust and respect for one another. Partial access to the information system was blamed on the lack of trust and issues of client confidentiality.

Withholding information

In situations where care was provided over a long period, and often for intensive periods, care workers become the ultimate information gatekeepers who filtered information selectively to care managers whose task was to create and maintain existing clients' social care records. Care workers' primary motives were to protect the privacy of the client:

'You don't want to be telling them (*care managers*) every little detail. Whereas we would tell each other (*care workers*) to look out for this, or the client may have

difficulty there... little personal things that you don't want to be unkind about, but you need to perhaps, tell each other about.' (Care Worker20)

The researcher observed that independent, private sector care workers often took full responsibility for a client's problems and perceived it unnecessary for care managers to be involved in a particular situation.

‘And I, then I talked to CA21 about it on the phone and I said, what shall we do? Are we going to tell him? Then he'll have to organise the insurance, and... And so we discussed it and she um said, I don't to think, it's going to make, if it's going to make him ill, make his eye worse, there's no point so we discussed it and then um from there then uh we knew we uh, needed to speak to his family. And um we had to make a quick decision until we could get in touch with his family and then I phoned his daughter. Now, we dealt with that.’ (Care Worker20)

The impacts of not passing on the information may not be felt until a new care worker is sent into the setting inadequately informed, because the care manager had not been made aware of changes to a client's personal details by the existing care workers. Where care is organised and provided directly through local authority social services, information sharing was heavily promoted through care worker / care manager monthly meetings and the provision of mobile telephones to care workers. Local authority care workers must also log-in to, and log-off from, care sessions with a care co-ordinator. Care worker / care manager meetings had been abandoned by the private sector agencies surveyed, and no logging-in was required. Care managers did, however, have daily contact with client situations where there were significant problems.

The nature of the information

The nature of some key client information makes it difficult to express and record.

Knowledge and information held by care workers is often tacit in nature. Care workers were unable to articulate their knowledge about a client: 'I just know' or 'you know' were common responses to questions about a care worker's knowledge. One attempted to explain her mechanism for interpreting client needs:

'... only by observation can you know... right paracetamol, uh fybogel, lactulose, coffee, squash.' (Care Worker1)

The researcher's field notes revealed her own tacit knowledge and the difficulties of sharing it with others:

'I tried to show Care Worker24 without CL1 (*a client*) in the harness and it seemed to me a very logical and simple to use piece of kit...' (Observation notes)

In reality, it took many months of close working with this care worker and the harness before she became competent with it and handling the client. Formal training in the use of harnesses and hoists was often provided in ideal situations, and in the home, with less space, and different floor coverings, use of harnesses and hoists for lifting clients required practice and learning how to adjust for different clients and different situations. Over time with a client, individual care workers build up a vast repository of client information that is not always formally recorded: 'I have got it all in my head.' (Care Worker4) Some used a 'mental checklist' to deal with what they need to know. Care managers expect care workers to assume the role of a detective, seeking missing bits of information to fill the gaps after their initial assessment or recognising changes in the client situation. Care workers interpret and recognise non-verbal signs indicating a client's need or mood, which aids their handling of a client or situation. The significance of this knowledge is not recognised by the care worker until asked for a particular piece of information. As seen above the information often remains within the care setting or between certain care workers. The information that care managers have to work with will be, at best, incomplete. If one of the key issues in social care recording is what information was known at a specific point in time that informed the decisions that were made then, and to record those decisions and service provisions, then clearly time points have to be agreed to assess whether changes have in fact taken place. Old and /or partial information can become dangerous information for which care managers cited examples where clients' safety was jeopardised.

Resistance to electronic information?

Care managers and care workers alike distrusted electronic information. Care managers and social workers in the local authority had negative experiences of a client information system that was often 'down' and had limited capability. They also lacked formal training in the use of electronic information systems and the local authority depended on the cascading of training by one or two people with informal interests in IT. Older-aged care managers in the private sector were wary of electronic information and had limited IT skills, and they too depended on informal training. Care workers became distressed when the word computer was

mentioned yet several stated they shopped via the Internet and were often observed text messaging on mobile telephones.

Discussion

Existing proposals for the Electronic Social Care Record [10] focus on the need for a care plan to have a minimum content definition (para. 3.10) and indicate the problems of granularity and consent (para. 3.6, 3.7). This study suggests that in some homecare settings, where the care teams are well established, homecare staff tend to filter information, to protect client confidentiality, but with the result that important information may sometimes not reach the formal record. Care planning is a process of negotiation initially. Existing proposals also focus on the concept of the 'document' in social care, but more account needs to be taken of existing methods (log books, post-it notes on fridge doors) that were observed as means of sharing information. These are very similar to the 'scraps' [13] of information nurses may use as part of personal recording of care. The informal record, the 'scrap' is the record that is used in practice and in this setting vital as a means of passing on information to other care workers and health professionals. What is a 'document' to a care manager may not be a meaningful way of monitoring care for a homecare worker. Homecare workers might have concerns about clients that they wanted to discuss, but which they did not wish to record in full, permanently.

However, the main difficulties are in the assumptions made about roles and responsibilities for some of the care processes. Using the process modelling notation described by Ould [19] the problems are easier to see. Ould's scheme for process modelling captures the roles involved in collaboration, as well as providing a framework for a process architecture that identifies and rigorously queries processes. Ould distinguishes Units of Work (UoWs) as the essential business entities having a lifetime that the organisation has to tend. The essential business entities are things that have to be done, and these generate responsibilities, to handle a unit of work. Inevitably units of work have to be related to each other to get all the work of the organisation done, and the process for one unit of work will generate, or have consequences for other units of work. As a first cut at the essential business entities in the homecare setting, we might have 'care plan', 'care session' and 'care needs assessment'. In setting out the process architecture, 'care needs assessment' may generate one or more 'care

plans. A ‘care plan’ in turn generates one or more ‘care sessions’. The useful element of Ould’s Riva business process modelling framework is the differentiation of types of ‘case process’. Every UoW has a case management process that handles the flow of cases of that UoW. The basic service relationship for ‘care plan’ and ‘needs assessment’ is as illustrated (Figures 1 and 2).

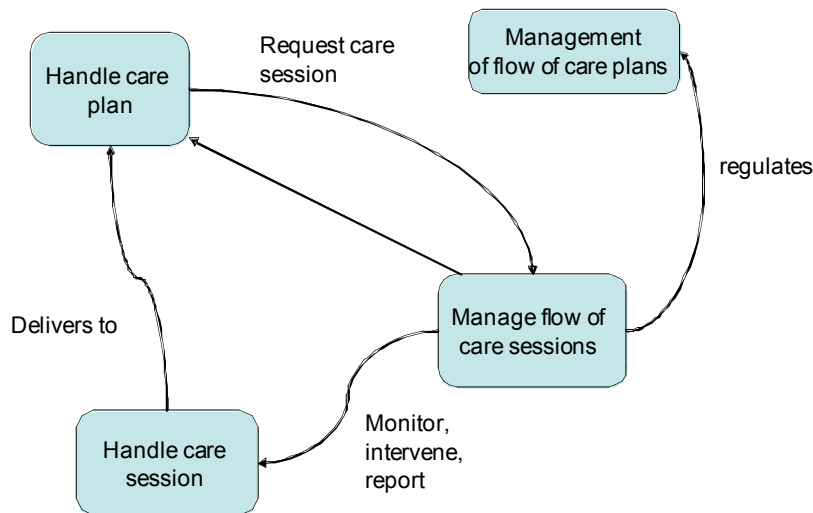


Figure 1 Care plans and care session service relationship

If in this setting we can say that the ‘Management of the flow of care plans’ is something that the ‘care plan’ does for itself, and is part of the ‘care plan’, then the diagram can be simplified to a task force relationship, omitting the ‘Managing the flow of care plans’. Similarly the ‘Managing the (flow of) needs assessments’ might be omitted as a separate process, if it can be subsumed within ‘needs assessment’. This will depend on the organisation or organisations involved. For one care agency, dealing with their set of clients, the management of needs assessment could be viewed as part of the needs assessment process. For a local authority dealing with several care agencies the full service relationship diagram makes more sense.

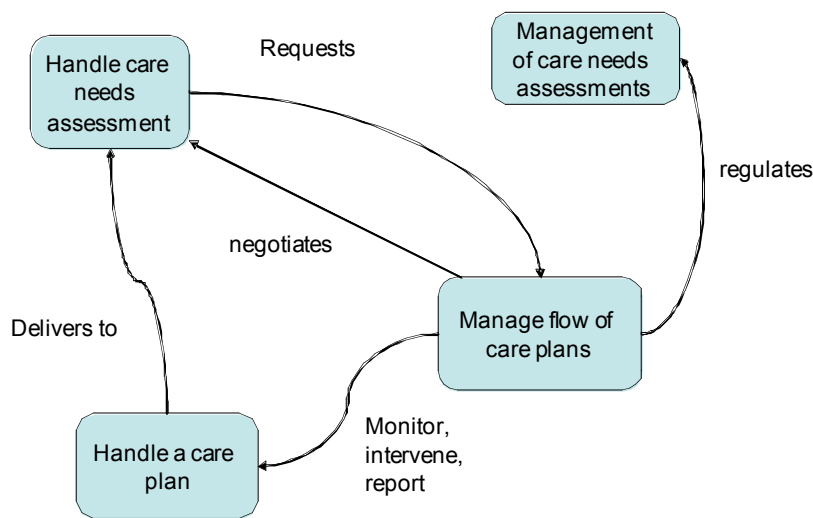


Figure 2 Care needs assessment and care planning service relationships

The process architecture can be simplified if it is possible to encapsulate the case management process into the case process. For example, is it more appropriate to fold the ‘Management of Care Sessions’ into ‘Handle a Care Session’? Is it sensible to fold the ‘Management of Flow of Care Plans’ into ‘Handle a Care Plan’? This probably needs more modelling of the roles involved. The roles here (according to Riva modelling conventions) are Care Manager, Care Worker, Family Representative.

Looking at these diagrams, in relation to the ethnographic findings, makes it possible to see where some of the misinterpretations are arising. In the care agency, the ‘management of the flow of care planning’ was not, perhaps, given the importance it actually deserved, and there was perhaps the assumption that ‘Handle needs assessment’ activated ‘Handle care plan’ in a very clear cut manner. In fact, the negotiation process was very important, and it would be necessary to ensure that the process was kept discrete. Turning to care plans and care sessions, the difficulties here concern the diffuse role responsibilities. In some instances, the care worker role is taking responsibility for part of the management of care sessions, whereas the care manager role may be assuming that the responsibility is theirs. From the care manager perspective the monitoring, activating, requesting of reports might be seen as something the care manager did. In fact, the team of care workers assumed responsibility for

many of those activities, and as far as they were concerned, that responsibility was often subsumed within the handling of a care session. One of the difficulties in modelling such situations is the drift of responsibilities over time. In this particular care agency there was an emphasis on continuity of care, with teams of care workers often working with one client over a long period of time. At first, the care manager might have retained more of a controlling role, but over time, the care workers assumed responsibility. This was acknowledged within the agency by the designation of key workers for particular clients, and they were assumed to be the care staff with most knowledge about the client. More in-depth modelling of the situation would be required to assess whether the 'key worker' could be viewed as a defined role. In addition, the process of 'Handling a Care Plan' generated other informal information exchanges and conversations, which were important, but it is questionable whether integrated electronic records could or should support that type of working record.[20] The failures of communication can be attributed to different perspectives on the responsibilities of those involved, but the problems for care workers new to a particular setting, and the risks involved, for both care worker and client, demonstrate the need for careful modelling of the processes. The care agency studied was needs-driven, rather than task-driven, and it is likely that process modelling and roles would be different in other agencies or in care directly controlled by the local authority.

Other studies of the co-ordination of care and the user of computer based record systems include the more rapid collaboration required in an intensive care unit. [21] However, this study also indicates the different needs of different groups of users, some requiring retrospective summaries of what has happened, and others requiring prospective information. For homecare, managers' interest in monitoring may largely be to confirm what has been done, whereas for the care workers, the interest is more in guiding what to watch for, and what should be done. Any electronic record would need to accommodate these two different perspectives.

Conclusions

Effective care depends on trust, and care workers may find it easier to build trust with other care workers for the effective management of long-term care for some of the homecare clients. Managers may be cut out of the monitoring loop and that can impact on management

of care for a client, when a new care worker is introduced into the situation, and is given misleading information about requirements by a manager. The use of process modelling illustrates that discussions are required to establish the boundaries of roles and responsibilities, and these need to be carefully articulated before embarking on changes to recording. Regular formal reviews might avoid some of the problems associated with care workers assuming, often quite unconsciously, roles and responsibilities concerned with managing care plans into their own handling of a care plan. The ethnographic findings also emphasise the importance of the negotiation process at the start of care provision for a client, when needs assessment is an ongoing process and requires care workers to liaise closely with managers. The formal care record may record the outcome of discussions, but there must be recognition of the importance of observation, negotiation and discussion in the assessment process and in care planning, and the different perspectives of care workers and care managers.

Acknowledgements

The authors thank the Arts and Humanities Research Council for funding the PhD studentship, and we thank all the clients and care staff who contributed in many different ways to the research. We are grateful to the referees for their constructive comments. We are not aware of any conflicts of interest. The research gained approval of the local research ethics committee in Cardiff, and was conducted according to their guidance.

¹ Department of Health (England). Modernising social services. London: Department of Health, 1998.

² Department of Health (England). Analysis of targets for older people. Target- Public Service Agreement on home care.
<http://www.dh.gov.uk/PublicationsAndStatistics/Statistics/StatisticalDevelopment/ReferralsAssessmentsPackagesCare/fs/en>, accessed 4 February 2007

³ Department of Health. Contact hours of home help and home care provided by sector. England. Table C5. http://www.performance.doh.gov.uk/HPSS/TBL_C5.HTM, accessed 4 February 2007

⁴ Statistical Directorate, National Assembly for Wales. Social Services Statistics Wales 2003. <http://www.wales.gsi.gov.uk/statistics>, accessed 4 February 2007

⁵ Cawthra L. Older people's health information needs. *Health Lib Rev* 1999;16:97-105

⁶ Payne S, Kerr C, Hawker S, Hardey M, Powell J. The communication of information about older people between health and social care practitioners. *Age Ageing* 2002; 31:107-117.

⁷ The Royal Commission on Long Term Care. With Respect To Old Age: Long Term Care – Rights And Responsibilities. Alternative Models of Care for Older People. Research Volume 1, The Context of Long-Term Care Policy. London: The Stationery Office, 1999.

⁸ Pinelle D, Gutwin C. Awareness-based scheduling in a home care clinical information system. AMIA 2003, Symposium Proceedings, p.519-523.

-
- ⁹ Department of Health. Information for social care. London: DoH, 2001
- ¹⁰ Department of Health. Defining the electronic social care record. Consultation draft. London: DoH, June 2003
- ¹¹ Firth P. Preparing for healthcare and socialcare integration: some current barriers to ICT-based sharing of information. *Br J Healthc Comput & Inf Manage* 2003;20:21-24
- ¹² Cooper J., Urquhart CJ. Confidentiality issues in information systems on social care. In K. Grant, DA. Edgar, M. Jordan. Reflection on the past, making sense of today and predicting the future of information systems, 9th Annual Conference Proceedings (UKIAS), Annual Conference 5th-7th May 2004, Glasgow Caledonian University, Glasgow
- ¹³ Hardey M. Payne S, Coleman P. 'Scraps': hidden nursing information and its influence on the delivery of care. *Journal of Advanced Nursing* 2000; 32(1):208-214
- ¹⁴ Currell R, Urquhart C. Nursing record systems: effects on nursing practice and health care outcomes. *Cochrane Database of Systematic Reviews* 2003, Issue 3. Art. No.: CD002099. DOI: 10.1002/14651858.CD002099.
- ¹⁵ May J, Ellis-Hill C, Payne S. Gatekeeping and legitimization: how informal carers' relationship with health care workers is revealed in their everyday interactions. *J Adv Nurs* 2001; 36(3):364-375.
- ¹⁶ Wicke D, Coppin R, Payne S. Teamworking in nursing homes. *J Adv Nurs* 2004; 45(2):197-204.
- ¹⁷ Kinney ED, Kennedy J, Cook CA, Freedman JA, Lane KA, Hui SL. A randomized trial of two quality improvement strategies implemented in a statewide public community-based, long-term care program. *Med Care* 2003; 41(9):1048-1057.
- ¹⁸ Sin HC. Expectations of support among White British and Asian-Indian older people in Britain: the interdependence of formal and informal spheres. *Health Soc Care Community* 2006; 14(3):215-224.
- ¹⁹ Ould M. Business Process Management: a rigorous approach. Swindon: BCS, 2005.
- ²⁰ Fitzpatrick G. Integrated care and the working record. *Health Informatics Journal* 2004; 10(4):291-302.
- ²¹ Reddy MC, Dourish P, Pratt W. Coordinating heterogeneous work: information and representation in medical care. In *Proceedings of European Conference on Computer Systems in Cooperative Work (ECSCW'01)*. Bonn, Germany, 16-20 September, 2001, 239-258.